



Welcome to our June 2022 e-Newsletter and to our expanding global community

We hope that you find the articles in our June Newsletter inspiring and energising – ‘working better together’ is the way forwards and is so neatly encapsulated in this African proverb:

‘If you want to go fast, go alone – if you want to go further, go together’

An introduction from Prof Chris Scott

The only constant in life is change and this is especially true for the dynamic members of the Task Force!

Congratulations to ***Prof Claudia Saad-Maghalães*** from Brazil who has kindly agreed to replace Prof Helen Foster as Co-Chair on the Task Force. Helen, who has led selflessly from the front and conceptualised the very idea of a Task Force, will continue to be actively involved, focusing on the further development and dissemination of the PMM suite of educational materials. Claudia brings to the TF a lifetime of experience in leadership, advocacy and clinical care in paediatric rheumatology and I personally look forward to working with her very much in this new role. Helen has been appointed to the Global Alliance for MSK Health International Coordinating Council, so she will be able to make further great contributions to our cause from her new position!



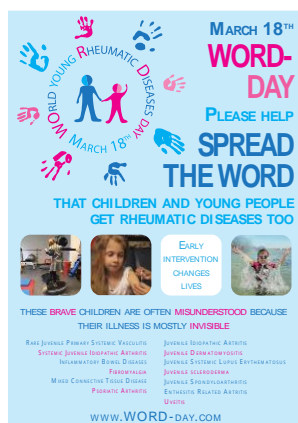
May 2022 – the **PMM Portfolio** (www.pmmonline.org) transferred from Newcastle University, UK to PReS. The PMM Portfolio includes the PMM website and other resources (e.g. pGALS app, all the pGALS translations, e-Learning Modules) which will remain free and open to all as teaching and learning resources. The Task Force is integrally involved with PMM and has many members on the recently formed PMM Editorial Board led by Helen Foster. A PMM Scoping Review has been done and a further 2022 iteration of PMM is now well underway to expand content – take a look ! PMM will soon have a fresh design and will be formally launched at PReS September 2022. We are planning for the PMM Editorial Board to meet in Prague during the PReS meeting.



After a few years of virtual meetings, it was very refreshing indeed to be able to present an update on the activities of the Global Task Force at the Recent EULAR conference in Copenhagen. It was a reminder of how valuable in person contact and discussion in our work. Delivering this talk was a great honour as it reflects the efforts of all of you, who have done things that are quite incredible-all virtually and all despite the terrible pandemic

and lockdowns. We have much to celebrate and be proud of dear friends and colleagues. Let us aim to celebrate together at PReS in Prague!

WORD-Day 2022 – March 18th – Reports



The Paediatric Task Force continues to actively support WORD Day (World young Rheumatic Diseases Day) to raise awareness about rheumatic diseases in children and young people and that early diagnosis and access to right care can radically improve their lives.

The first WORD Day in 2019 was a great success and each year has got better and bigger.

PReS and ENCA held webinars on March 18th and feedback was excellent – these were recorded and are available <https://wordday.org/webinars/> - please share these details to your colleagues and networks.

Word day 2022: a step forward in Algeria

Prof Djohra HADEF and Prof Samy SLIMANI



FEAS, the Algerian Foundation for Arthritis and Rheumatism ENAYA, organized an awareness day on therapeutic education on “Chronic Inflammatory conditions”. FEAS has recently created a new office in Batna to help patients in this city and the eastern region of the country in their daily fight against the disease. This was their first event in Batna. The program was varied with the participation of experts, doctors and patients to discuss together the concerns of patients with clear presentations on many rheumatic diseases with the participation of eminent rheumatologists, Prof Slimani, Dr. Boukredera and Dr. Khaled. JIA will be addressed by Prof HADEF, a paediatric rheumatologist.

For the second year in a row, Le Souk Batna (Scientific association of medical students) celebrated the World Day in a special entertaining party at the department of Pediatrics - CHU Batna-; medical students shared activities and interactive games, supporting young patients in their fight against the disease.

Introducing patients and their families in a formal way into the treatment process is crucial to improving chronic disease management. For this proposal, the celebration of World Day was an opportunity to move forward with our young patients in our country.

REGISTER FOR THE WORD DAY WEBINAR (Part 1) PRS 

Webinar 1: When to suspect a paediatric rheumatic disease and refer
Friday 18 March, 18:00 CET



REGISTER NOW

REGISTER FOR THE WORD DAY WEBINAR (Part 2) PRS 

Webinar 2: Together, how can we help children and young people live well with a rheumatic disease?
Friday 18 March, 20:00 CET



REGISTER NOW



This meeting was also an opportunity for parents of patients to found the association of children with rheumatic diseases, the first in Algeria, in order to create a permanent communication bridge and to be their spokesperson.

Check out www.wordday.org for more information and follow-on Twitter (@WORDDAY_org) and Facebook.

There are lots of free resources from the WORD team that can be downloaded and personalised. <https://wordday.org/promotional-toolkit/#1581170447417-64402c96-4b6b>

PRs2022



28th European Paediatric Rheumatology Congress

20 - 23 SEPTEMBER 2022
PRAGUE • CZECH REPUBLIC

Congress www.pres.eu/pres2022
PRs www.pres.eu

State-of-the-Art Therapeutic Strategies in Paediatric Rheumatology: Targets, Pitfalls and Challenges



Selection of major topics:

- Immune dysregulation
- Lessons learned from COVID-19
- Molecular signatures of inflammation
- Understanding rheumatic disease evolution
- Treat-to-Target - Fiction or reality
- Challenging treatment strategies
- Novel Therapeutic challenges
- Prediction models

Selection of invited speakers:

Marta Alarcón Riquelme	Mo Lankarani
Paul Bastard	Alberto Mantovani
Alexandre Belot	Isabelle Melki
Petter Brodin	Peter Nigrovic
Andreas Diefenbach	Mike Ombrello
Andrea Doria	Grant Schuler
Dirk Elewaut	Rae Young
Bodo Grimbacher	+ 30 more distinguished experts

PRs 2022 – update from Prof Claudia Saad Magalhaes, Brazil

The 28th European Paediatric Rheumatology Congress (PRs 2022), will be in Prague from 20-23 September 2022 with the overall theme “*State-of-the-art therapeutic strategies in pediatric rheumatology: targets, pitfalls and challenges* “. Apart from updates on management strategies, the congress will have a strong scientific component on novel concepts of immune dysregulation and the potential translation into clinical practice.

It is the largest scientific event dedicated to the field of Pediatric Rheumatology worldwide. In 2021, the 27th PReS virtual congress, attracted more than 1350 participants. We are confident this year's congress, planned in a hybrid format with either face-to-face or recorded sessions, will offer an opportunity to exchange scientific ideas within an attractive program. It can revitalize the scientific community by bringing together friends from all over the world in the exciting atmosphere of the beautiful city of Prague, in the historical surroundings of Charles University. The congress venue is just 10 minutes away from the city centre and the highlights of Prague are all close by.

The Young Investigators Meeting (YIM), led by Emerge (EMerging Rheumatologists and Researchers) PReS trainees and young scientists, will be held on 19-20th September, offering exceptional learning and networking opportunities to the next generation of researchers and clinicians.

The most up to date information can be found on the [website](#) with reduced-fees-early registrations for both, virtual and face-to-face formats. The programme grid and detailed programme is now published; 69 guest speakers have confirmed their participation to 25 scientific live-streamed plenary and parallel sessions, working –parties business meetings, including the Global Task Force Meeting. All scientific and sponsored sessions, as well as the Young Investigator Meeting (YIM), with oral and poster presentations, will be held in Prague. Recorded sessions will be available up 31 of December.

The highlights of face-to-face participation will be the long waited peer-interaction and network for oral and poster presentations. Up to now 516 abstracts have been submitted. Innovative educational sessions with 90-minutes guided training mini-workshops about Nailfold Capillaroscopy, Data Analysis (RStudio), ERN-RITA Clinical Management System and the Health Professionals training about Outcome Measurements on Physical Activities on the first day of the Congress. There will be practical and guided training with experts instructors and preparatory material to read in advance. The post-Congress activity will be the Pediatric Muscle Skeletal Ultrasound Course.

The 2022 PReS meeting will provide a wonderful opportunity of inter-disciplinary learning in partnership with patients, parents, young scientists and trainees, as well as clinicians and health professionals.

Last, a short note about humanitarian crisis in Ukraine. PReS condemns all forms of violence and war affecting children, young people and their families. Acknowledging the extremely difficult war situation in Ukraine, PReS waived registration fees for participants from Ukraine and there will be a motion to raise awareness about pediatric rheumatic diseases care during the war.

Title: “PAFLAR education programme: Never stop learning because lives never stop teaching”

Prof Wafa Hamdi, Tunisia



PAFLAR is proud and more than happy with the goals achieved with the education pillar of our strategic plan. We are now at our second year of a successful monthly webinars and preparing our second virtual congress. Indeed “Never stop learning because lives never stop teaching” can be the PAFLAR motto for this mission.

PAFLAR monthly webinars

The **Pediatric Society of the African League Against Rheumatism (PAFLAR)** is committed to effect strategies and programs that impact the well-being of children with Rheumatic and Musculoskeletal Diseases through education, research, advocacy leading to a world where children with rheumatic and musculoskeletal diseases (RMDs) have the same and optimal chance to live, grow and develop like their other normal counterparts, especially in Africa.

Neonatal Lupus
"Recent Updates & Literature Review"

SPEAKER
Dr. Carlomagno Raffaella
Cheffe de clinique in pediatric rheumatology
LAUSANNE UNIVERSITY HOSPITAL (CHUV) AND GENEVA
UNIVERSITY HOSPITAL (HUG), SWITZERLAND

MODERATOR
Prof. Mohammed Hassan
Associate professor of Rheumatology
TANTA UNIVERSITY, EGYPT

MAR 2nd 2022
6-7 PM-CAT

In association with
KENYA PAEDIATRIC ASSOCIATION
IIAR

To RSVP: info@paflar.org
Join Through: <https://us02web.zoom.us/j/84460819752?pwd=UHF0T2JmTnBKVXVrZDkvNmRlYjFZZz09#success>

@paflar | Paflar Africa | Paflar Africa Afrique

Paediatric Society of the African League Against Rheumatism

representative and participating countries have their national coordinators who have formulated a program of topics. Speakers from each of the regions share their experiences and educate healthcare workers in Africa about Paediatric Rheumatology using case-based discussions. PAFLAR also

In order to achieve this goal, PAFLAR embarked on monthly paediatric rheumatology webinars held via Zoom® every 1st Wednesday of the month. Africa has been divided into 5 zones i.e **Northern Africa, Western Africa, Central Africa, Eastern Africa and Southern Africa** regions. Each region has a lead

Dare to Rise with Excellence in 2022

SPEAKER
Dr. Patricia Murugami
Global Leadership Catalyst, Founder and Chief Executive Officer
BREAKTHROUGH LEADERSHIP TRANSFORMATION & RISE
SCHOOL, KENYA

MODERATOR
Dr. Angela Migowa
Paediatric Rheumatologist President of PAFLAR
THE AGA KHAN UNIVERSITY MEDICAL COLLEGE, EAST AFRICA
KENYA

FEB 2nd 2022
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Paediatric Society of the African League Against Rheumatism

invites renowned international speakers every year to host two webinars to promote exchanges and collaboration with the international community of pediatric rheumatology. *Three Webinars have been organized so far this year.* Dr Patricia Murugami from Kenya tried to show us how to rise the excellence in 2022, Dr Rafaella Carlomagno from Switzerland presented an overview of neonatal lupus and Prof. Kenza Bouayed presented difficult cases of Kawasaki disease.

E-posters are prepared and circulated via social media and PAFLAR website prior to the webinar in order to create awareness for the topic and allow participants to register and receive the Zoom® link (<https://paflar.org/activity/>). A voting application is also available to enhance speaker-participant interaction for the meeting through the **PAFLAR website** (<https://paflar.org>). Case-based presentations are discussed with participants who are regulated by a moderator. The record of these sessions and the footage is availed through the PAFLAR website for future reference (<https://paflar.org/activity/>). Thereafter, a post-evaluation survey is shared online with the participants to obtain feedback about the sessions and on how to improve the PAFLAR webinars and allow them to obtain an *electronic* certificate of attendance.

Hosting the monthly PAFLAR webinars has had a positive impact on our community and we have more attendees signing up for our sessions, nearly a hundred attendees each session. In the first three webinars of 2022 we have had a total of 262 participants. We are more than happy to have colleagues from outside of Africa join us for our webinars this year from countries such as Uruguay, India, Canada, USA, Palestinian Territory Occupied, United Kingdom, Ukraine, Australia, Ecuador, Saudi Arabia, Iraq, Bermuda, Colombia, Ecuador, Kuwait, Indonesia, Qatar, Thailand, Yemen, Venezuela, Peru, Norway, Barbados, Bangladesh, Viet Nam, Pakistan, Romania, Guatemala, Mexico, Turkey and France.

A rich and varied program is scheduled for the rest of year 2022 and made available to attendees through website and social media every month.



Kawasaki disease
"Difficult cases"

SPEAKER
Prof. Kenza Bouayed
Professor of Pediatrics, Paediatric Rheumatologist
HÔPITAL UNIVERSITAIRE MÈRE ENFANT A. HAROUCHI,
CHU IBN ROCHD, CASABLANCA, MOROCCO

MODERATOR
Dr Ajibade Adenitan
Consultant Physician/Rheumatologist
FEDERAL TEACHING HOSPITAL, GOMBE, NIGERIA

APR 6TH 2022
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 KENYA PAEDIATRIC ASSOCIATION


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 @paflar  Paflar Africa  Paflar Africa Afrique

Paediatric Society of the African League Against Rheumatism

2nd PAFLAR virtual congress
"Paediatric rheumatology in
Africa: challenge, innovate
and grow"

The first PAFLAR congress held virtually on July 28-30, 2021, provided our participants with the opportunity to exchange experiences, share knowledge, and enhance networking. In our first congress, 755 individuals from 65 countries registered for the congress this included: 94 paediatric rheumatologist, 167 Adult rheumatologists, 218 Pediatricians, 11 Adult physicians, 20 Fellows, 53 general practitioners, 95 Resident, 95 Other health care workers. Daily attendance ranged from 150 to 200 attendees. We received a total of 160 abstracts from 11 African countries (Algeria, Kenya, Tunisia, Morocco, Egypt, Senegal, South Africa, Libya, Tanzania, Nigeria and Ghana), India, the UK and the USA. Out of the 160 we published 97 successful abstracts with oxford press. The congress held over three days, featuring several sessions of best clinical practice and scientific rich program has been carried out covering many areas of pediatric rheumatology with particular emphasis on the scope of the discipline across Africa. We have been honored and fortunate to have Prof. Rolando CIMAZ (may his soul rest in Peace) as the first speaker of the congress with an overview of pediatric vasculitis. This year PAFLAR offer another exciting opportunity to learn, deliberate, and collaborate. The 2nd PAFLAR virtual congress will be held between 29th of June and 1st of July 2022. Our theme “Paediatric rheumatology in Africa: challenge, innovate and grow” addresses the current problems in the Paediatric Rheumatology domain in Africa and how to surmount them. Registration for the congress is open (<https://paflar.org/2022-paflar-congress/>). The preliminary program is now available on PAFLAR website (<https://paflar.org/wp-content/uploads/2022/03/Preliminary-Program-of-2nd-PAFLAR-Congress.pdf>). Experts from



around the world have been invited as guest speakers to lead and enrich the discussions. The 2022 PAFLAR congress edition promises to be extraordinary, phenomenal and outstanding.

PAFLAR Board Members
<https://paflar.org/>



Publications report by: *Associate Prof Cylie Williams, Australia*

BMC Medical Education

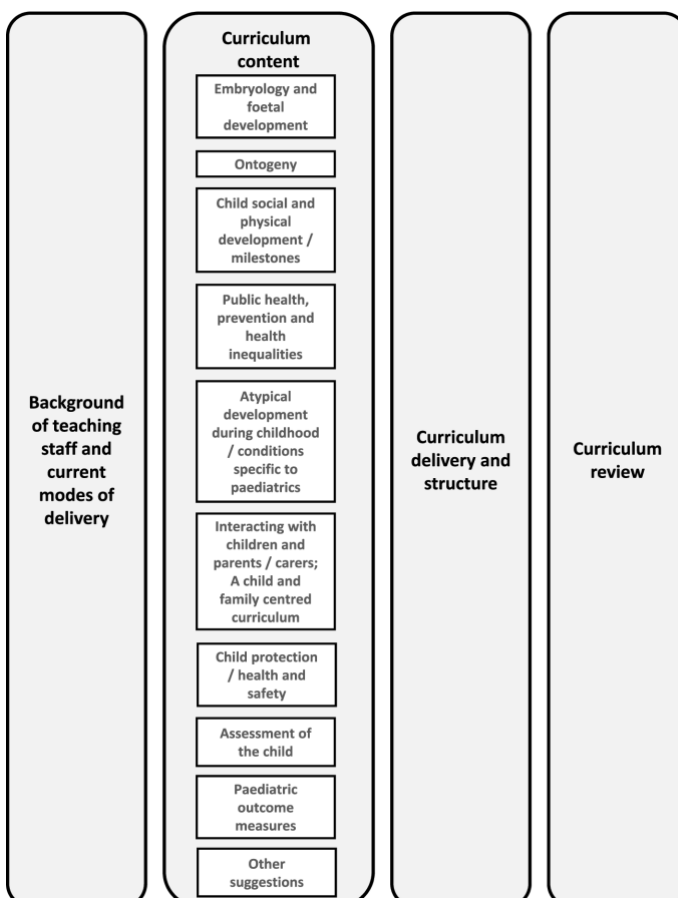
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Research | [Open Access](#) | [Published: 24 February 2022](#)

A step in the right direction: Delphi consensus on a UK and Australian paediatric podiatry curriculum

[Julie Reay](#) , [Cylie Williams](#), [Chris Nester](#) & [Stewart C. Morrison](#)

Key points:



- Aligning international curricula provides many opportunities for consistent health care practices and the international workforce

- Podiatry is a small, but growing workforce, with approximately 9% of caseloads dedicated to optimising children's lower limb health.

- Consistent new graduate knowledge is essential for the delivery of safe and evidence-based podiatry practice and benefits children's health outcomes.

- This research developed four key themes for the different elements of curriculum (Figure) and how these might be embedded into a program of study across the two countries.

- This research also provides benchmarking opportunities for courses to align content and improve consistency of practice across graduates.

Link to full article:

<https://bmcmmeduc.biomedcentral.com/articles/10.1186/s12909-022-03138-8>

¹ Monash University, School of Primary and Allied Health Care. Australia <https://research.monash.edu/en/persons/cylie-williams>

² Peninsula Health, Allied Health Research, Frankston, Australia

The WHO Essential Medicine List and appointment of the first PReS Global Health Research Fellow!



The World Health Organisation Essential Medicines List (EML) informs policy makers about which medications should be prioritised within national formularies and is particularly important for countries with limited resources.

The Task Force is working with colleagues to develop the case of need to revise the EML. While our initial applications in 2020 for Tocilizumab, Anakinra and Intra-articular steroids were not met with success, we were recommended to submit a revised application.

Thanks to a generous donation from PReS, we are delighted to have recruited Dr. Waheba Slamang from South Africa as the first ever **PReS Global Health Research Fellow** to work with Prof Chris Scott and Prof Helen Foster along with our team of volunteers from the Task Force.

Waheba is an experienced clinical researcher and paediatric rheumatologist – she will coordinate our efforts to assemble the revised application to the WHO EML Committee in time for the deadline November 2023. We will keep you updated as to her progress. We wish her all the best!

Christiaan Scott, Nicola Smith, Rebecca James, Ben Whitehead, Rochelle Green and Helen E. Foster. Letter to the Editor. *Pediatric Rheumatology* 2021 19:10 Revising the WHO Essential Medicines List for paediatric rheumatology

Foster HE, Scott C. Update the WHO EML to improve global paediatric rheumatology. *Nature Reviews Rheumatology* 2020



Australia holds Parliamentary Inquiry into childhood rheumatic diseases – Report from Ms Victoria Allen, Chair, Juvenile Arthritis Foundation Australia

The Australian House of Representatives Standing Committee on Health, Aged Care and Sport has conducted an inquiry into childhood rheumatic disease in Australia. The terms of reference of the inquiry included the prevalence of the disease, research into causes, the

impacts on children and their families (including health, social, educational and economic impacts), access to medical services, best practice quality of care and treatments, and awareness of the diseases among healthcare professionals and the broader community. The Juvenile Arthritis Foundation Australia (JAFA) campaigned for this ground-breaking inquiry given the lack of access to diagnosis, care and treatment for children in Australia with rheumatic diseases and their families.

The Standing Committee received over 130 written submissions, and heard evidence in public hearings from medical professionals and families alike. These submissions, along with the terms of reference and the Standing Committee's interim report can be found at https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases

The Standing Committee's interim report was tabled in Federal Parliament on 31 March 2022 and made 15 comprehensive recommendations for reform in Australia. Most notably, the first recommendation was to triple the workforce by 2030 in order to bring Australia's workforce to minimum international standards. Further recommendations included establishing multidisciplinary centres of care in all capital cities, outreach care for regional and rural areas, greater education for GPs together with the wider medical professional, schools and community, ensuring access to disability support and new medications, and the establishment of a national registry.

JAFA and the Australian Paediatric Rheumatology Group have combined forces to lobby for the adoption of the recommendations which would revolutionise the access to care and treatment for children with rheumatic diseases and significantly reduce the burden of these diseases.



A Report from Ms Catherine McCormack, CEO Arthritis Kids South Africa

We are thrilled to launch our guide to raising a child with JIA. The guide, intended for parents and caregivers of children diagnosed with juvenile idiopathic arthritis, touches on various subjects, including, 'My child has JIA. What's next?', 'Starting medication', 'When to call the doctor', 'Medicating for pain' and a comprehensive FAQ. The guide also includes places to note medicine review dates and when and how to contact the child's doctor and is currently available in two South African languages. Hard copies can be obtained directly from paediatric rheumatologists; adult rheumatologists and other specialists treating children with JIA can request a delivery from Arthritis Kids SA by emailing admin@arthritiskids.co.za. A digital version of the guide can be found here: <https://drive.google.com/file/d/1OmDJuRSxsoNBaFJvIhIH3dIsTyU7PMx0/view?usp=sharing>

IMPORTANT NOTICE

The Paediatric Global MSK Task Force has support from the Paediatric Rheumatology European Society (PReS) to disseminate our e-Newsletter further to the extended PReS community so not only to the PReS members. This is great news as we will be able to reach many new audiences as their list is currently 10,000+.

So, if you are not on the PReS list already, in order to receive our Task Force e-Newsletters in the future you will need to sign up to the PReS mailing list. Please note that being on this list is free and not just for the paediatric rheumatology community and has appropriate governance around data protection.

The link is below:

<https://www.pres.eu/pres2022/index.html>

Please pass this important message on to your clinical colleagues and networks as our next e-Newsletter will be sent out via PReS. The Task Force mailing list will cease to be active after June and all data will be erased.

The Paediatric Task Force 'Call to Action'

To Raise Awareness

- About the *many* children and young people around the world with MSK problems.
- About the considerable long-term impact of *untreated* MSK conditions starting in early life: *impact* on young people, their families, carers and society with a breadth of impacts on quality of life.
- That many conditions are *treatable*; long term disability can be avoided thus reducing 'cost' to individuals and society,

To Identify, Share and Promote exemplar solutions to better access to 'right' care

- Models of clinical care and care pathways.
- Education and training to expand the workforce capacity.
- Patient and public engagement and participation.

To Promote healthy joints and bones

- Through lifestyle choices (e.g. diet, exercise).
- Reduce the risk of injury.
- Reduce the long term risk to bones and joints.

Our Structure and Membership

- The Paediatric Task Force works in partnership with organisations to address global challenges in paediatric MSK health.
- We have co-chairs and a steering committee comprising multi-professional representation from paediatric rheumatology, paediatric orthopaedics, allied health and parent advocacy groups.
- All roles are voluntary and non-remunerated.

The paediatric global musculoskeletal task force - 'towards better MSK health for all'. Foster HE, Scott C, Tiderius CJ, & Dobbs MB. *Pediatr Rheumatol Online J*. 2020 Jul 14;18(1):60. doi: 10.1186/s12969-020-00451-8.PMID: 32664961

Improving Musculoskeletal Health for Children and Young People – a 'call to action'. Foster HE, Scott C, Tiderius Carl J., Dobbs MB and members of the Paediatric Global Musculoskeletal Task Force (Elizabeth Ang, Sirirat Charuvani, Wendy Costello, Marja Kinnunen, Laura B. Lewandowski, Angela Migowa, Simon R. Stones, Soamarat Vilaiyuk and Kate Webb). *Best Pract Res Clin Rheumatol*. 2020 Jul 26:101566. doi: 10.1016/j.berh.2020.101566. Online ahead of print.PMID: 32727697 , <https://doi.org/10.1016/j.berh.2020.101566>

Paediatric Global MSK Task Force (<http://bjdonline.org/musculoskeletal-problems-in-children-and-young-people/>)

Pediatric Rheumatology European Society (<https://www.pres.eu>)

Paediatric Musculoskeletal Matters (<http://www.pmmonline.org>)

Follow us: Twitter <https://twitter.com/paedmskglobal>

